

Being a Parent With a Traumatic Brain Injury

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<https://msktc.org/tbi/factsheets>

TBI Factsheet

Parenting can be a very rewarding experience, but is often challenging. This factsheet includes tools for how to overcome parenting challenges that might be encountered after a TBI.

Introduction

Being a parent can be one of the most rewarding experiences in a person's life. It can also be one of the most challenging experiences. Parenting requires many skills, such as good communication, patience, attention to detail, and a good memory. Parents also need to be flexible and able to handle complex emotions. Juggling the responsibilities of being a parent with other life demands can be hard for anyone. But having a traumatic brain injury (TBI) can make it especially difficult. This factsheet includes information about how being a parent with a TBI can be difficult and offers suggestions for overcoming parenting challenges.



Keeping Everyone Safe and Healthy

Keeping your family safe and healthy is one of your top priorities as a parent. A parent's biggest fear is that they are not keeping their kids safe. Sometimes after a TBI, a parent may *lose confidence* in their ability to keep their kids safe. But in most cases, they are still very capable. Many books and websites provide tips on how to make a home safe, how to protect your child from danger, and what children need to be healthy. The following tips can help you care for your child, in spite of coping with TBI-related changes:



The Traumatic Brain Injury Model System Program is sponsored by the National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living, U.S. Department of Health and Human Services. (See <https://msktc.org/tbi/model-system-centers> for more information).

- **Do things a little different.** Know yourself and what you can and cannot do. If your body moves differently than it did before the TBI, you may need to change how you carry your infant or hold your child's hand when you cross the street. If your vision has changed, you will need to do some childcare tasks differently. Talk to an occupational or physical therapist about alternate ways to do some tasks and devices that can help you. For example, you may use a stroller in your home or have your child hold onto a rope or strap that is attached to your belt when you cross the street.
- **Get input from others.** It is a good idea to talk to another adult you trust about how to childproof your home and come up with rules for safety. This can help you think of ideas; it can also boost your confidence.
- **Set up a healthy routine.** Children of all ages need a good sleep schedule, healthy food, and regular checkups with their doctors. To help you keep track of these, use daily or weekly schedules and checklists.



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- **Set rules** in your home that encourage good habits. For example, you might not allow cell phones in the bedroom at bedtime. Use your pediatrician as a resource and support in how to care for your child.
- If you have complications from the TBI, such as seizures, **create a plan for what to do if a crisis occurs.** For example, you may need a medical alert button. You may also need to teach your child to dial 911 in case of crisis.
- **Learn to recognize when you need help.** Sometimes being a good parent means knowing when you can't keep your child safe on your own. When this happens, ask another trusted adult to help look after your child.

Supporting Your Child's Education

During childhood and adolescence, school is a central focus of life for children and their parents. School educates children for the future and teaches them social skills. As a parent, you want to support them as they learn to be independent and help them succeed. It can be hard to *keep track of the schoolwork, due dates, and meetings.* You are expected to *communicate* with teachers and other parents. Sometimes you have to manage conflicts between your child and other children or teachers. Your child will have times when they feel proud and times when they feel frustrated.



Here are some tips to help you interact with the school and support your child:

- **You may wonder if you should disclose your TBI.** You don't need to share this information with everyone. But it is important to let the teacher or other main contact at school know if you need them to communicate differently with you. For example, tell them if you need them to highlight the most important information, or if you need to get requests through email and not in your child's backpack.
- There are many forms to complete. If this is hard for you, **set up a way to complete forms** with your family and friends or with the school. (Maybe they can be done verbally or carried over from year to year.)
- **Checklists can be helpful** for you and your child. Teachers often provide these for students when they start school. As children get older, they encourage kids to make their own checklists. Help your child make a checklist of assignments and tests, with dates. Post this where you can both see it and review it with your child each day. You can also list any materials that your child needs for projects. As they get older, put your child in charge of making the checklists.
- Children will reach a point where they are studying things that their parents don't understand. Don't worry if you don't fully understand what they are studying. You can still **help them study.** First, be supportive and encourage them to meet the deadlines on their assignment checklist. Second, make sure they have the tools they need. This may include books, teacher resources, and a quiet place to study and do homework. This may include monitoring time spent on the Internet that is not related to schoolwork.
- **Is your child struggling academically?** Are they frustrated or are their grades poor? Sometimes they just need you to listen to their frustrations. However, if your child can't manage an assignment, guide them to ask their teachers for help. As they get older, their schools may also have resource centers and tutors. Remember that you have a community of support for your child, including your social supports and the school.



- For young children, **reading together is important**. If your TBI makes it hard for you to read, ask your child to read to you. You can also share books with pictures, while encouraging your child to create their own story from the pictures.

Managing Your Child's Activities

As a parent, you must coordinate many activities for your child. These include doctors' appointments, social activities with family and friends, and leisure activities, such as team sports, piano lessons, and scouts. TBI can make it hard for you to manage your child's activities. For example, fatigue may make it hard to start or continue a leisure activity. You may also have a hard time planning, organizing, and remembering activities. This can make it hard to keep track of activities, set up transportation, and help with events. Here are some tips:



- **Use a calendar or agenda** to track appointments. Include when sign-ups are due, when and where practices and events are, and when you need to call for appointments. Take advantage of reminder calls offered by doctors' offices.
- You will likely feel tired before your child does. Know your limits. **Pace yourself**. You will need to decide what you can help with and when to say *no*. Your child can do some activities without you.
- **Use checklists** with your child to make sure you bring everything they need to the appointment/event.
- **Work with other parents**. Working together can help you overcome expected and unexpected challenges. If there are things that you can't do, see if you can coordinate with other parents so that they do those tasks, and you do others. For example, if the other parent can drive, you can offer to bring sliced oranges to sports practice. For some, hiring help is an option.
- **Take note of changes in your child's interests** after your injury or a change in your health. They may need encouragement or support to stay with activities that they enjoy.

Emotional Support for Your Child

You may think that forming an emotional bond with your child occurs naturally, but it takes work. As children go through different developmental stages, their interests change, along with how they interact with others. Over time, they grow into independent people with their own needs and likes. In addition to keeping up with their emotional changes, children need discipline and rules to keep them safe. Changes in thinking and emotions caused by TBI can make it hard to give them the structure and support they need. For some, TBI can make it hard to recognize their child's emotions, especially when they rely on facial expressions and body language. TBI can also affect your ability to recognize your own emotions and to monitor how you express them. Forming an emotional bond with others also requires your attention and mental energy. TBI can cause rapid mental fatigue and make it difficult to pay attention. So, after a long day, your ability to respond to your child's emotional needs may not be the same as before your TBI.



Here are some tips to help provide emotional support to your child:

- **Take time to listen**. Set aside a regular time for check-ins. Check in with your children about how they are feeling. Ask "How has your day been?" If they respond with one-word answers, such as "good," gently probe for more detail with something like, "Can you tell me something that made you happy?"



- If you have a young child who is learning new tasks, watch them and say aloud what they are doing. For example, if your child is playing with Legos, say, “You are putting the blue Legos together to make a train,” or “You decided to build a tree.” This lets your child know that you **notice what they do and supports them**.
- **Make a few simple rules.** Writing them down can make them clearer to you and to your child. Written rules can help you communicate the rules consistently when you are under stress. Teach these rules by example. Children are more likely to follow what you do than what you tell them. Show them what you want them to do.
- If you have trouble recognizing good behavior, work with another adult **to identify what “good” looks like.** Look for that behavior in your child and praise them for it.
- If you find yourself losing your temper with your child, **give yourself a time-out.** If you make a mistake or hurt someone, apologize. Explain to them what you are doing. This is good way to be a role model for your child. **Make notes about things that your child seems to take an interest in.** When you are feeling alert, ask them to share a favorite song with you or ask them about their favorite sports team. Schedule an activity around their interests (e.g., a concert, shopping, or watching an online video). Let them know you care about what is important to them.
- **Talk to them about the consequences** of their actions. Use language they can understand. For example, point out to a toddler that their friend is sad. Ask a teenager how an action affects a friendship and whether they want to keep the friendship.
- When children are upset, it helps them *and* you to **name the emotion.** You can give them choices so they can pick the emotions that fit. For example, ask, “Are you feeling sad or are you feeling jealous?” Also share your emotions honestly when you can.
- If you feel that your child is more distant since your TBI, talk to them about this. **Let them know that you understand that your injury may be scary to them,** and that it may have changed some things about you. Invite your child to share their feelings about this. Share your feelings about the TBI, too. You may also involve other family members to this discussion.
- If your child is acting out, **work with another adult who cares** about your child to set rules. Also work with them to problem-solve difficult behavior issues.
- **If you think your child is struggling emotionally, get help.** Are they withdrawn? Are they acting out a lot? Do their mood swings seem severe? Did their grades drop suddenly? Your pediatrician or your school can help direct you to get help from therapists, counselors, psychologists, etc.

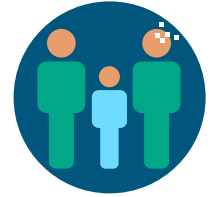


Co-Parenting When Your Partner Has TBI

Co-parents may be together, separated, or no longer in a relationship. No matter what their status is, they may share responsibility for raising a child. Co-parents may have a mutual commitment to promote and support their child’s healthy development from infancy through adulthood. Like parenting, co-parenting is hard work and can be stressful. It requires a lot of time, communication, and problem-solving, which is challenging for all parents and becomes even more so for a co-parent with a TBI.



There are many ways that you can help your co-parent with a TBI. Here are some tips:



- Learn about TBI and its effects so that you can understand the mental, physical, and social challenges your co-parent faces. Understand that the journey after TBI has many **ups and downs, which affect the whole family**. TBI is an invisible disability and can be easy to forget in the moment, yet remembering and using these strategies and resources can lead to greater success for all.
- The parenting responsibilities that your partner had before the TBI may be too much now. Talk to your partner about a **weekly schedule or calendar that spells out the responsibilities** that you both feel are realistic and that each of you will take on. Post the schedule and review it each week.
- Your partner may not be aware of the impact of their actions—or their lack of action—in any given situation. **Understand** that what they do or don't do may not be on purpose.
- To **nurture your relationship**, schedule time for just the two of you to be together. This should be separate from your time with your children.
- Learning how to deal with the effects of your partner's TBI can be hard for you on many levels. *Get the outside support that you need* so that you remain supportive of your partner and your children.
- Realize that every happy family looks a little different—there is no one way to be a happy family. Love, attention, good communication and understanding how your TBI is part of the family are keys to success.

Resources for Parenting With a TBI

Living with Traumatic Brain Injury (TBI): <https://msktc.org/tbi>

Parenting After Brain Injury:

<https://www.headway.org.uk/media/3998/parenting-after-brain-injury-e-booklet.pdf>

Positive Parenting Tips: <https://www.cdc.gov/ncbddd/childdevelopment/positiveparenting/index.html>

Ultimate List of Resources for Co-Parents: <https://talkingparents.com/blog/ultimate-list-of-resources-for-co-parents>

Traumatic Brain Injury Factsheets: <https://msktc.org/tbi/factsheets>



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